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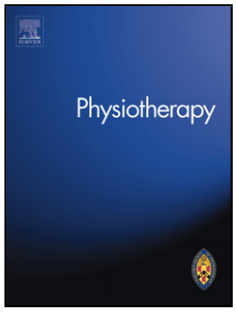

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Physical activity engagement in early rheumatoid arthritis: A qualitative study to inform intervention development

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Physical activity engagement in early rheumatoid arthritis: A qualitative study to inform intervention development

Abstract

Background

Physical activity (PA) in patients with rheumatoid arthritis (RA) is lower than in the general population. PA can improve physical function in RA, decrease chronic inflammation and reduce pain, without adversely affecting disease activity.

Objectives

To explore patient's views on approaches to delivering PA programmes and inform a programme to maximise functional ability through long-term engagement with PA.

Methods

Qualitative data were collected via three focus groups which explored the views of people with RA of their PA support needs following diagnosis; experiences relating to PA; motivators and facilitators to support PA engagement and the suitability for people with RA of evidence based PA programmes designed for other long-term conditions.

Results

Study participants (15 female, 4 male; 59.9 (standard deviation (SD) 10.3) years) had a mean time (SD) since diagnosis of 44 (34) months. Data analysis yielded 4 key themes relating to PA programmes 1) Why people join and why they drop out 2) venue and timing 3) what people want to do and hear 4) who should deliver programmes and how.

Conclusion

Patients with RA are interested in PA programmes 6 to 12 months after diagnosis, which support safe exercise and provide expert physiotherapist input. Recommendation by trusted health professionals and promotion of the benefits for 'people like me' would positively impact recruitment and retention. Key elements of the programme include proficient, safety-oriented exercise guidance, RA education, peer support, relaxation, coping strategies and self-set goals. Findings indicate that a group-based programme with a social aspect would support adherence.

Physical activity engagement in early rheumatoid arthritis: A qualitative study to inform intervention development

Background

Rheumatoid arthritis (RA) is a chronic inflammatory auto-immune disease that primarily affects synovial joints and can lead to loss of function and decreased mobility. Physical activity (PA) in RA is lower than in the general population (1) and has been shown unequivocally to be associated with work disability and reduced physical function (2). Research has shown that high intensity training programmes (3) and class based exercise (4) can improve physical function in RA, while PA decreases chronic inflammation and reduces pain (5), all without adversely affecting disease activity.

PA is defined as "any bodily movement produced by skeletal muscles that results in energy expenditure [above resting levels]" (6). In addition to the benefits associated with RA, regular PA can reduce the incidence of a wide range of chronic conditions, promote physical and mental health and improve perceptions of fatigue and quality of life (7). Despite all these potential benefits only 13.8% of people with RA exercise more than 3 times per week (8), illustrating the impact of chronic conditions where pain and other physical and psychosocial limitations are factors (9, 10).

Fatigue, pain, decreased mobility, lack of professional input, inaccessible facilities, surgery, medications, potential embarrassment, fear of falling and the psychological effects of the disease have been identified as barriers to PA in RA (11).

Even when pain free, people with RA often fear that PA will exacerbate their symptoms (12). Overall, these findings suggest a need to identify programmes that support long term engagement with PA for recently diagnosed people with RA to minimise inappropriate health beliefs and prevent unnecessary reductions in function. This assertion is supported by National Institute for Health and Care Excellence (NICE) guidelines which indicate that people with RA should have access to specialist physiotherapy to encourage regular physical exercise (13).

Basing PA interventions on appropriate health behaviour change models has been shown to increase the likelihood of success and is recommended by NICE (14, 15). There is a dearth of evidence regarding health behaviour change models to promote long term engagement with PA interventions in inflammatory arthritis, with the quality of the research poor and the findings somewhat inconsistent (16, 17). However there have been successful theory-based interventions to increase PA in other long term conditions; elements of which may be transferable to people with RA (18, 19).

The UK's Medical Research Council recommends a development-evaluation-implementation model for the development and testing of complex interventions (15). The engagement of the intended patient group is central to ensuring that interventions are as appealing and acceptable as possible. The ultimate aim of this study is to develop and test an intervention (Promoting Engagement with Physical Activity – Rheumatoid Arthritis (PEPA-RA)) based on Self Determination Theory (SDT) (20), to promote long term engagement with PA by people with RA. The intervention would target patients up to two years from diagnosis in an attempt to prevent unnecessary physical de-conditioning due to inactivity and promote good PA habits (21). This paper reports the results of the formative research conducted to inform the development and design of PEPA-RA.

Specifically, in this study, we sought to: 1) understand motivators and facilitators of engagement in PA post diagnosis of RA; 2) identify factors that might affect programme recruitment and retention; and 3) explore people with RA's perceptions of a variety of PA programmes based upon existing evidence in other long-term conditions to identify key PA programme elements.

Methods

Design

Data were collected via three focus groups conducted during July and August 2014. Group participants were recruited by researchers from rheumatology clinics at University Hospitals Bristol NHS Foundation Trust (UHBristol) and the Royal National Hospital for Rheumatic Diseases, Bath (RNHRD) rheumatology clinics. In addition a research nurse reviewed patient notes at the RNHRD and contacted those who met the inclusion criteria by telephone.

Focus groups were used as the data collection device as they allow participants to refine and test their thoughts and responses against those of others, and to explore and challenge their peers' opinions, so generating data of additional depth (22). Qualitative approaches are highly appropriate for understanding complex personal and social issues such as engagement in physical activity and the influence of chronic disease on PA and are useful when, as in this case, there is limited existing knowledge.

Participants

Study inclusion criteria were 18 years plus and with a diagnosis of RA from a rheumatologist, according to ACR criteria (see Appendix A) (23) within the last 5 years. This was considered to enable good recall of the early stages after diagnosis. Age and diagnosis were procured from patient notes. Date of diagnosis was self-reported at recruitment.

Procedure

Patients who met the inclusion criteria were provided with participant information sheets and a reply slip. On receipt of a completed reply slip the patient was allocated to a focus group. Participants' travel expenses were reimbursed.

Participants were purposefully sampled to reflect a range of age and gender. Due to the relative heterogeneity of the research population in relation to the subject of enquiry, a sample size of approximately 20 was proposed to be sufficient to collect data of an appropriate breadth and depth (22).

The focus group interview guide was semi-structured and designed to explore patients' views of their PA support needs following a diagnosis of RA; their experiences relating to PA and motivators and facilitators of engagement in PA. Following a discussion of these issues three different PA programmes were presented to the focus groups (see Appendix B). Two of these were based upon successful interventions that the authors had experience of delivering, namely ESCAPE (Enabling Self-Management and Coping with Arthritic Knee Pain Through Exercise) (19), a programme for patients with arthritic knee pain based on Bandura's Social Cognitive Theory (24) and TREAD-UK (TRial for Exercise And Depression in the UK) (18)

for people with depression and based on Self Determination Theory (SDT) (20). The third intervention, PEPA-RA, also based on SDT, was an intervention outline designed by the authors with input from additional members of the clinical team and two patient research partners. All programmes proposed a combination of support for behaviour change, education and PA (See Table 1). Participants were invited to comment on these interventions; explore their suitability for people with a recent diagnosis of RA; identify limitations; suggest alternative content and delivery mechanisms; and critique support materials. The interview guide was reviewed by the study Patient Research Partner, a person with RA and a patient at one of the research centres. A pilot interview was conducted to refine the guide prior to commencing the focus groups and as a result some of the interview guide language was revised to be more colloquial. It was subsequently deemed fit for use by the research team.

JW conducted three focus groups, with FC acting as scribe; both are experienced qualitative researchers. JW has a non-healthcare background and a research interest in physical activity while FC is an experienced researcher in the field of RA and a qualified physiotherapist. This enabled the research team to respond effectively to issues raised in the fields of both physical activity and RA. No relationship between the interviewer or scribe and the participants existed prior to the focus groups and neither researcher was involved in the care of participants. Each group lasted approximately 80 minutes and was recorded using a digital voice recorder, transcribed and coded to ensure anonymity and confidentiality. The final focus group revealed no unique information so theoretical saturation was deemed to have been reached.

Ethics

Ethical approval for the study was provided by the NRES Committee South Central - Berkshire B committee, REF: 14/SC/0118. Written informed consent was obtained for all participants prior to focus groups commencing.

Analysis

Data analysis took an interpretivist view to allow for understanding individuals' opinions and views of PA within the context of their RA diagnosis, as well as understanding the intersection of these views within a shared group environment (i.e., similar disease diagnosis). All transcribed text was entered into NVivo (Version 10, QSR, Southport, UK) for electronic coding and data retrieval. Inductive thematic analysis was used to identify the main themes across the groups. Emerging themes were verified through discussion and a coding framework based on these themes was developed (25) . Transcripts were coded by JW and reviewed by the study patient research partner. The coding was reviewed by the three other authors and existing codes were refined and new codes were identified (see Table 4 for an example of the coding process from quotes, codes, categorization and themes). The emergent themes and sub-themes were reviewed by AH, an experienced qualitative researcher, and the interpretation and analysis were discussed and agreed by all four authors. Salient quotes that captured the essence of the themes were extracted and summarised in tables using a framework approach (25).

Results

Twenty-seven people were recruited. Eight dropped out prior to the focus groups being held. The final sample comprised 19 participants (15 female, 4 male), with a mean age (SD) of 59.9 (10.3) years and patient reported mean time (SD) since

diagnosis to be 44 (34) months. RA diagnosis was ascertained from patients' clinical notes. A summary of participants' demographic information is shown in Table 2.

The three programmes presented to patients (ESCAPE, TREAD and PEPA-RA) produced a variety of comment. To avoid duplication the results are presented here as themes that were generated across all three programmes, rather than by each individual programme.

The data analysis yielded 4 key themes: 1) Why people join and why they drop out 2) venue and timing 3) what people want to do and hear 4) who should deliver programmes and how.

Pseudonyms have been used for the participants and the characteristics of each are detailed in Table 3

Why people join and why they drop out

Participants suggested that hearing about other patients' experiences and resulting health benefits would increase the likelihood of their attending a PA programme.

> *'It might be nice to know that somebody …like you who seem to have quite an acute problem that this really made a difference'. (Participant G).*

Fears that exercise could exacerbate disease and associated joint damage needed to be addressed. The presentation of PA as for 'people like me' via images and case studies was proposed, with the social aspects of a group setting largely regarded as positively influencing recruitment and adherence.

'I think you need to push the social side of it so it's not like a structured exercise'. ((Participant I)

Support from healthcare professionals to participate in PA, and their endorsement of the programme, were considered to be influential.

Barriers to taking part included symptoms of RA such as pain and fatigue.

'You will find that a lot of people won't turn up because they are not feeling very well'. (Participant R)

Pragmatic measures suggested to support adherence included reminder phone calls or text messages.

Programme venue and timing

The second theme related to scheduling and included time from diagnosis, session frequency, duration and timing.

Between 6 and 12 months after diagnosis, when a stable drug regime had been established, was the preferred timing for a PA programme.

'If you are not settled on drugs and you are hurting and you are tired and you feel like death warmed up you are not going to want to do anything apart from eat biscuits'. (Participant G)

Views on frequency were disparate. ESCAPE's twice weekly sessions were seen as a large time investment by most but a few acknowledged that such intensity may be required for impact.

'Twice a week for six weeks that's a lot ….and you get away from your kids'. (Participant D)

Some participants felt that PEPA-RA, a less intense programme over a longer period, offered greater flexibility,

'When it's a longer one having not so many contact sessions is quite good because it still allows you some flexibility'. (Participant G)

whereas a lengthy programme such as TREAD could be a deterrent to engagement.

'Six to eight months I think mmm that's really long for me to tie myself into something'. (Participant G)

Preferred session timing depended on situational factors such as employment status and access to childcare while fatigue later in the day was cited as a barrier to evening sessions.

What people want to do and hear

Education and RA related group discussions, supervised exercise sessions, home exercising, expert input and goal setting emerged as the major sub-themes within programme content.

Relaxation and coping strategies, medication and its effects, RA flares, fatigue and pain were all regarded as important education and discussion topics. An opportunity to meet and share thoughts with other people with RA was also positively rated by most participants.

> *'I don't really know anybody that has it and I think it would be nice to have that opportunity… just to talk about those things that affect you.' (Participant J)*

Supervised exercise was considered positively, with sessions providing a safe and supportive environment. Training to ensure safe and effective home exercising was also valued as a flexible option which could supplement group sessions and continue post intervention.

> *'If you are at home and you have been shown how to do it and you know you get results from doing it that would motivate to do it as well'. (Participant D)*

However concerns about the motivation and self-discipline required for exercising alone were raised.

> *'You would have to be quite self-disciplined wouldn't you to do it at home'. (Participant K)*

Support from peers and 'experts' was perceived to be an important element of a successful PA programme. Being advised by a physiotherapist or someone perceived as an 'expert' would instil confidence and help to address concerns regarding injury or potential joint damage.

'It's really good … being watched by the people who know how to use these machines properly because otherwise you could end up doing more harm than good. I think I would feel much safer.' (Participant K)

Goal setting, as used in TREAD, ESCAPE and PEPA-RA, was regarded as motivational and '*a bit of a push*' but should clearly be patient developed as there were concerns about extrinsic pressures from peers and professionals.

'Everybody is at a different level and you have a group and you start discussing well you should be doing this ...I would feel there was pressure on me to do something that I didn't want to do.' (Participant E)

Who should deliver programmes and how?

The final theme was delivery including group sessions, telephone support and location.

TREAD, the PA programme including more telephone than in-person support, attracted polarised comments with the benefit of flexibility juxtaposed against a lack of relatedness.

You are almost on your own really with that aren't you? (Participant E)

A group setting was preferred by the majority but a small number of participants felt that the benefits were outweighed by the increased commitment required, the lack of flexibility and a preference not to identify primarily as an RA patient.

'I prefer the group because … it's quite nice to have other people around you with the same problems, doing the same thing'. (Participant K)

'Well I have been to one (group) …all we did was sat around and talked about what was wrong with us'. (Participant O)

Peers were seen as sources of experiential and practical advice on issues such as managing flares; while peer support, potentially via a buddying system, could be important in maintaining motivation and engagement.

'It's quite nice to get to know other people…it's that sort of morale support that can be really, really useful'. (Participant G)

Incorporating TREAD style telephone support to maintain motivation and ongoing group programme engagement was viewed positively.

'It would be good to have telephone support because I know me I will just slide down the scale a bit until oh we have got another group session coming'. (Participant A)

An easily accessible location for sessions seemed important, with access to transport a common issue. There was also support for holding sessions outside a hospital setting in a community/leisure centre which could help familiarise participants with facilities that they might otherwise lack the confidence to access.

> *'You are going (to the gym) with someone who understands what you can do and they could help you with a programme … you could … feel a little bit more confident'. (Participant M)*

Discussion

This study explored the views of people with RA regarding the feasibility and acceptability of potential PA programmes. The focus groups indicated that people with RA would be interested in a PA programme designed to improve physical function. Common with other interventions, key issues were overcoming barriers to engagement, scheduling sessions at an acceptable time, location and frequency, and delivering appealing and appropriate content (19). These findings are also consistent with recruitment and retention issues in general health behaviour change interventions, where ill-health, transportation issues, time conflicts and session timing and content impact engagement (26, 27). These findings clearly illustrate the core challenges that need to be addressed in any PA intervention for patients with RA.

Recruitment is critical to the impact of any health-related programme. Referral by a health professional was regarded as a preferred form of recruitment, and has been shown to be effective among chronically ill populations (19, 28). It also provides reassurance regarding fears of disease exacerbation and increased joint damage (12). Also in common with previous

observations, belief in the benefits of PA in managing RA would be likely to affect motivation to participate (29) so should be emphasised in recruitment materials. A preference for exercising amongst relative equals was also reported (30). Therefore peer endorsement, case studies and the use of appropriate images that present the programme as being for 'people like me' were considered important. However, as in other studies, some participants preferred not to be viewed primarily as an individual with a disability, suggesting the inclusion of general health promotion content would be beneficial (31).

Consistent with the broader literature, potential health improvements were regarded as motivation to engage in physical activity (32). However exercise adherence is more often associated with enjoyment and social interaction (33). Indeed many participants considered the group-based elements of ESCAPE and PEPA-RA, which enabled the sharing of experiences and socialising, as valuable to on-going programme engagement. However the nature of RA means that patients' motivation to be physically active is affected by fluctuating disease symptoms such as pain and fatigue. Consideration needs to be given to methods of ensuring patient engagement despite a variable condition that challenges adherence. It may be that a programme combining group sessions with telephone/text/email support could provide appealing levels of peer contact, support and flexibility while maintaining sufficient contact levels to be effective. Further input from patients may be required to establish the best way to address this.

Most patients considered that between 6 and 12 months after diagnosis, when a stable drug regime had been established, was the ideal timing for a PA programme. Preferred session timing largely related to whether patients were in paid employment,

259 which made afternoon sessions (the generally favoured option) impractical. It may be that to recruit a working and non-
260 working cohort would require different timing options, and potentially different delivery methods.

261 Group participants presented disparate views on session frequency, highlighting the trade-off between flexibility and
262 effectiveness. The less frequent sessions of PEPA-RA were largely preferred to the twice weekly ESCAPE sessions.
263 However, a systematic review of reviews found that amongst the adult population in general greater PA intervention
264 effectiveness was causally linked with higher contact time or contact frequency (34).

265 Popular ESCAPE and PEPA-RA programme content included education and group discussions, relaxation and coping
266 strategies, supervised exercise sessions and guidance on home exercising. Expert input and peer support were highly valued
267 and have been widely shown to positively influence PA intervention effectiveness (34). Goal setting and monitoring, usually
268 effective in PA programmes (35, 36), were viewed by this population with some caution, eliciting fearful comments
269 regarding taxing goals being imposed by professionals and peer pressure. When introducing these concepts to those with RA,
270 it is clearly important to emphasise that these are patient-set goals, developed without extrinsic influence.

271 As with other groups where mobility may be compromised, an easily accessible location was advocated and a lack of
272 transport cited as a barrier to engagement (37). The largely telephone-based TREAD circumvented this barrier, but basing the
273 intervention in local community/leisure centres rather than a central clinical setting could also facilitate engagement. It could
274 also familiarise participants with amenities that they might otherwise lack the confidence to access, and which they could

continue to use long-term. However, to deliver programmes in this setting may require the training of appropriate healthcare professionals as rheumatology services are traditionally provided through secondary care.

Strengths and limitations

This study provides information on the factors that would affect the recruitment and retention of people with RA into a PA programme and input on programme design and content. We recruited across a broad section of patients through different recruitment strategies with the aim of developing an understanding of a phenomena (PA in RA) rather than making probabilistic generalizations to a population (38). A limitation of the study is that people who volunteer to participate in studies may differ from those who do not, in potentially important variables such as socio-demographics, attitudes to PA and the severity of RA. In addition some issues may not have been revealed as only three theory-driven programmes were included for deliberation, although commencing with broad discussion prior to discussion of the programmes allowed general themes to emerge.

Diagnosis of RA can occur after a long process of investigation and the exact date of diagnosis was not always clear from patients' medical notes. As a result we asked patients to self-report timing of their RA diagnosis. At recruitment all participants reported diagnosis in the last 5 years but at the focus groups four participants described earlier diagnoses. As both sets of data were self-reported we do not know which is more accurate. For a small number (3 female, 1 male) of participants a duration of more than 5 years since diagnosis may have affected the accuracy of their early RA recollections.

Conclusion

The data presented indicate that there is an interest in PA programmes for patients with RA, 6 to 12 months after diagnosis which support and guide safe exercising and provide expert input. Recruitment is likely to be positively impacted by recommendation or referral by trusted health professionals and a focus on the benefits for the target group and the programme's relevance to 'people like me'. Key elements include proficient, safety-oriented exercise guidance, RA education, peer support, relaxation, coping strategies and self-selected goals. Findings indicate that a group based programme with a social aspect would support adherence. Incorporating telephone support to maximise contact and maintain engagement when group participation is impacted by RA symptoms may be beneficial. Key issues that need to be addressed are accessibility, setting (primary care/community), session timing and how to offer flexibility while maintaining effective levels of contact. On-going patient engagement will be required in the further development and evaluation of this programme.

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398 **Table 1 Physical activity programmes presented to the groups for discussion**

Programme Name	Health Behaviour Theory	Programme duration	Patient Group	Frequency	Mode/Setting	Deliverer
ESCAPE	Social Cognitive Theory	6 weeks	Patients with arthritic knee pain	Twice a week (for one hour)	Group sessions in a secondary care setting Education/self-management discussion plus guided exercise	Physiotherapist
TREAD	Self-Determination Theory	6-8 months	Patients with depression	Up to 13 contacts over 6-8 months	3 face to face sessions in a community setting. Up to 10 telephone conversations	Trained physical activity facilitator
PEPA-RA (proposed intervention)	Self-Determination Theory	12 weeks	Patients with RA	5 sessions over 12 weeks	4 group sessions in a secondary care setting 1 individual session Education/discussion plus guided exercise	Physiotherapist

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Table 2 Characteristics of focus group participants (n=19)

	Range	Mean	SD
Age (years)	31-73	59.9	10.3
Self report time since diagnosis (mths)	1-120	44.3	33.8
Gender		**N**	**%**
Male		4	21
Female		15	79
Current work status		**N**	**%**
Part time or full time paid work		8	42.1
Student		0	0
Homemaker		1	5.3
Unemployed		0	0
Retired		8	42.1
Retired and receiving incapacity benefits		2	10.5

Table 4 Example of development from codes, categories to themes

Meaning unit	Code	Sub-theme	Theme

Participant A: ...and the motivation is there to push you to do it when you are doing it together. *Participant C: The other person isn't it?* *Participant A: Exactly yeah you encourage one another* *Participant E: Yeah I have been a couple of times without my sister and I have gone on less time instead of the 20 minutes I have only gone on ten minutes and come home like an hour before I should of.* *Participant C: Yeah you push each other along.*	Exercising together	Social support	Enablers of exercise

Table 3 Focus group participant profiles

Participant	Gender	Age	Months since diagnosis	Work status	Engagement with physical activity
Participant A	F	61	1	Paid Work	w g, e
Participant B	F	63	24	Paid Work	w, g
Participant C	F	66	36	Retired	w, s, g, c
Participant D	M	53	48	Paid Work	w, g
Participant E	F	42	120	Paid Work	w, g, gy
Participant F	F	71	36	Retired	h
Participant G	F	59	3	Retired	w, g, gy
Participant H	F	62	48	Paid Work	w, g, h
Participant I	F	52	48	Homemaker	w
Participant J	F	31	48	Paid Work	w, s
Participant K	F	63	24	Retired[1]	g
Participant L	F	73	24	Retired	g
Participant M	F	63	72	Retired	w, e
Participant N	M	60	84	Paid Work	w
Participant O	M	68	48	Retired	w
Participant P	M	69	Missing	Retired[1]	Missing
Participant Q	F	59	2	Paid Work	w, g, h
Participant R	F	Missing	108	Retired	w, g, c, h
Participant S	F	65	24	Retired	w, g, h

[1] Retired and receiving incapacity benefits
w = walking, s=swimming, g=gardening, e=exercise class, c=cycling, gy=gym, h=housework